Ep_QoL_LE-1_V1.6
THE COSTS EXPERIENCED BY CAREGIVERS OF CHILDREN BEING TREATED FOR CANCER IN NEW DELHI, INDIA

R.S. Arora [1], S. Mardakis [2], A. Tsimicalis [2], S. Bakhshi [3], A. Arora [3], H. Anis [4]. [1] *Max Super-Specialty Hospital, Paediatric Oncology, New Delhi, India;* [2] *McGill University, Ingram School of Nursing, Montreal, Canada;* [3] *All India Institute of Medical Sciences, Department of Medical Oncology, New Delhi, India;* [4] *CanKids...kidscan, Paediatric Psycho-Oncology Program, New Delhi, India*

Background/Objectives: The allocation of time and other resources is essential to enable the treatment of children with cancer. Existing research from high income countries indicate that families incur significant variable costs impacting their finances and lifestyle substantially. However, there is no research examining the costs of childhood cancer from families in India, which may impact families' decision to abandon their child's treatment.
Design/Methods: A qualitative descriptive study was carried out in one private and one government-run hospital in New Delhi. Semi-structured interviews were conducted with caregivers of children with cancer in English or Hindi. Interviews were transcribed verbatim, translated into English, and analyzed using a thematic approach.
Results: In total, 26 caregivers of 25 children diagnosed with cancer participated in the study. Caregivers described various direct, indirect and psychosocial costs associated with their child's cancer treatment. The primary sources of direct costs were hospital admissions, medications, food and travel expenses. Indirect or time costs involved managing their child's treatment and its side effects. Work hours, time spent with other family members and sleep were most affected by this commitment to caring for their child. Psychosocial costs included coping with the uncertainty caused by a cancer diagnosis, feelings of guilt and sadness as well as having to watch their children suffer. Family members, healthcare professionals, other caregivers and employers were named as sources of support for families. Cutting back on routine expenses and negotiating treatment options were described as strategies for coping with the financial burden of treatment. No families abandoned treatment or indicated that they intended to do so.
Conclusion: The results of this study provide avenues for healthcare professionals and institutions to develop interventions aimed at reducing the costs associated with cancer treatment. Further research into the relationship between direct, indirect and psychosocial costs and treatment abandonment is needed.

Ep_QoL_LE-1_V1.7
EXPOSURE OF UNDERGRADUATE MEDICAL STUDENTS TO THE SOCIAL DIFFICULTIES OF CHILDHOOD CANCER: DOES IT MAKE AN IMPACT?

Lakshmanan SakthiKumar, R.J. Yogesh Kumar, M.S. Latha, Julius Scott. *Sri Ramachandra Medical College and Research Institute, Porur, Chennai, India*

Background: Medicine, once considered a “noble profession” and “service”, seems to have, in recent times, lost the awe with which it was once associated. Society has abundant criticism for medical professionals; that they have lost the “human touch”, that they perform unnecessary investigations, and that they don't have empathy for their patients.
Nevertheless, in this era of medical curricula completely focused on teaching, the explosion of knowledge and advancements in medicine, it is regrettably observed that the code of ethics and professionalism is often disregarded.
Promoting public health with active involvement in local communities and Exposing medical students to the social difficulties of disease will be a tangible method to learn the psychosocial aspects of patient care. By being exposed to the patients even before they are qualified clinicians, the students hone communication skills, develop a more empathetic attitude towards their patients' struggles, and learn to take a positive approach toward their medical conditions.
Aim: To expose undergraduate medical students to the social difficulties and sufferings of children afflicted with cancer, and their families, from a financial, psychological, social and emotional perspective by starting a medical student-driven, pediatric oncology supervised foundation, and to assess its impact in a teaching university.
Methodology: **MedHope** is a non-profit, non-governmental organization started in 2012 at Sri Ramachandra Medical College and Research Institute by MBBS students under the guidance of the pediatric oncology faculty. MedHope tries to help the cancer-afflicted children in a **holistic manner**: the ***financial*** aspect is managed through fundraising events; ***social awareness*** through camps, seminars, blood donation drives and walkathons (on cancer days), and ‘***Adopt a Child’- a new initiative***, wherein groups of student volunteers emotionally ‘adopt’ the child and their family on a non-medical, non-monetary basis, akin to the role of an elder sibling/family friend for the duration of the child's treatment.
Results: A survey conducted recently among the medical students showed that 60% of them wanted to voluntarily participate in these activities. Among them, 75% were interested in blood donation and 60% interested in conducting fundraising and awareness programmes. 77 % of them felt that being a part of student support groups has helped them to become more patient-oriented, and that awareness of their patients' psychosocial issues would contribute to their patients' effective management.
Conclusion: While clinical skills are undoubtedly important for patient care, students should be exposed to the social aspects of medicine, and should be educated about the cultural difficulties of treating a disease, which will change their attitude towards patient management, instilling values of empathy and humanity, which will help them become “good doctors”. Medhope, and similar organizations will certainly be a model and paragon for India.

Ep_QoL_LE-1_V1.8
UNDERSTANDING ABANDONMENT IN THE TREATMENT OF RETINOBLASTOMA

Geeta Mandhani [1], Smriti Bansal [2], Sima Das [2], Manas Kalra [1], Amita Mahajan [1]. [1] *Indraprastha Apollo Hospitals, Delhi, India;* [2] *Shroff's Charitable Eye Center, Delhi, India*

Background: Abandonment and refusal of treatment continue to be significant areas of concern affecting cure rates for retinoblastoma in India. Systematic analysis of factors influencing this can help us focus on directed interventions aimed at addressing specific areas. In 2014, a collaborative ocular oncology and pediatric oncology service was initiated at Shroff's Charitable Eye Center, Delhi. In comparison with the preceding two years, patient numbers increased and though abandonment has reduced, it continues to be a major challenge. In the current study we have tried to evaluate various factors that could possibly influence compliance to treatment for this specific disease.
Methods: Data was collected on all patients who initiated treatment at this center for retinoblastoma over a two year period from June 2014 to May 2016 . Concerted efforts were made to track patients who had defaulted from treatment. Information was collected on sex, stage of disease, laterality, distance from the treatment centre, socioeconomic and educational status of the parents. Efforts were made to proactively contact families and identify factors that may have influenced compliance.
Results: During this two year period 84 (M:F:: 1.2:1.0) patients initiated treatment at this center. Most patients had advanced stage disease. All patients belonged to lower or lower middle socio-economic background. Of these 50 complied with all steps of treatment whilst 34 defaulted with at least one treatment component. Of these 34 patients, 7 were continuing to receive treatment at another centre. The remaining 27 (M:14, F:13) patients were analysed for possible factors influencing abandonment. Sex, stage of disease, educational status of parents, birth order of the child were not different in the patients compliant and those who defaulted. The mean distance travelled was higher for patients compliant vs those who abandoned (384km vs 312km). Financial and family issues were most often cited as reasons for failure to comply.
Conclusion: Abandonment continues to be the major factor affecting outcomes of Retinoblastoma. Social rather than disease specific issues are the main factors influencing compliance. Concerted efforts are now being made to enhance support and facilitation to families of children with Retinoblastoma at this center to further reduce abandonment.